

February 4, 2009

Dear Public Health Committee Members,

Thank you for this opportunity to testify favorably for H.B. 6200, An Act Concerning the Long-term use of Antibiotic Treatment of Lyme Disease. My name is Maggie Shaw and I am a registered nurse from the state of Connecticut.

I am here today to testify on behalf of myself, my husband and my children. All five of us have been seriously affected by a disease that a handful of people decided, does not exist. This came about after millions of dollars had been devoted to researching it and documenting not only the existence of Lyme disease, but the devastating affects it could have on both humans and animals. They called it **Chronic Lyme disease**.

The current "rule book" for Lyme and tick borne-diseases, at least the one most widely accepted by insurance companies as their, "cost effective resource", was designed by a small panel of members of the Infectious Diseases Society of America (IDSA), who, according to the results of an investigation by our Attorney General in Connecticut, had vested interests in the outcome, along with significant conflicts of interest. This guidelines, better known as the IDSA's medical guidelines for the treatment of Lyme disease and its authors have stated for years that Lyme disease was easy to diagnose and easy to cure. My family and many others in this state are living proof that this is definitely not the case.

The Infectious Diseases Society guidelines denied my family a diagnosis of Lyme disease and then it denied us adequate treatment. Our diagnosis, which for the most part relied entirely on blood tests rather than our health care provider's clinical judgment, was totally missed. Our lab test results, as many can be, were false-negative.

My daughter was the only one in the family who presented with bulls-eye rashes. She had seven of them and was treated for 21 days without question, yet she never quite recovered. This was in spite of the IDSA guidelines promise of a cure for this short-term treatment.

My other family members weren't so lucky, if that is the proper use of the word. When they were infected they did not have many objective symptoms, things you can see and measure like a rash, frank arthritis (swollen knee), Bell's palsy, or positive lab tests for the agent *Borrelia* (bacteria that causes Lyme) in their blood or cerebral spinal fluid. According to the IDSA guidelines, you had to have specific markers, my family did not and the disease was allowed to progress.

Instead of the guideline's list of easy to spot symptoms, my family had the other common manifestations of Lyme disease; joint and muscle pain, headaches, fatigue, cognitive difficulties and psychiatric presentations- things the doctors, especially in a short visit, could not easily measure or see. For the majority of my family, the IDSA guidelines failed miserably. They didn't allow for adequate treatment, nor did they fulfill their promise to improve our symptoms- instead, they disabled my entire family.

While we attempted to get help for our worsening conditions, we were never informed that there was another standard of care that would, had it been offered for use, afforded us the proper treatment at the time it was most needed. The International Lyme and Associated Diseases Society (ILADS) formulated by treating physicians that address treatment for disease which persists beyond a short course of antibiotics and allow physicians to exercise clinical judgment in diagnosis and treatment. Physician reliance on the IDSA guidelines destroyed our health, our rights as patients and my right as a parent to make an informed consent for treatment for my children. The financial debt has been astronomical for my family.

At one point, due to my families continuing ill health, I asked for a meeting with the pediatric center, the one that missed my children's diagnosis. For my effort, and after seven years as patients at that facility, we were asked to leave the practice and find another doctor to treat our children. As a task force leader for many years I have heard of similar cases. If parents so much as inquire about treatment for their sick children beyond what the restrictive IDSA guidelines allows, rather than risk their licenses, pediatricians have asked families to leave their practice. Our doctors do not want to be brought up on charges for not following the rules or be responsible for our children when they continue to get sicker and lapse into the advanced stages of Lyme disease.

As a Task Force leader I have been privy to the plight of many others in their tragic experience with Lyme disease and the co-infections. The experiences of the thousands of people that I have spoken with are frighteningly similar to my family, many so much worse.

There are children who have missed a majority of their childhood due to this disease, many missing months or years of school. In Newtown, in one year reported to our school nurses, there were 58 cases of Lyme disease, 118 tick attachments removed, and in that same year 7-8 children on Individual Education Plans (IEPs) related to physical or cognitive impairment due to Lyme disease. We have had close to a dozen children walking our school halls with IVs or PICC lines for long-term antibiotic treatment. This is not just Newtown; this could be any town in CT very, frightening.

Results conducted by the University of New Haven research team on the tick infection rates for Lyme disease in my hometown of Newtown revealed that 70% of ticks tested are infected with *Borrelia burgdorferi*, the bacteria that are the causative agent of Lyme disease. Please consider the fact that this bacteria that causes Lyme is a spirochete very closely related to syphilis please also consider the effects syphilis can have on the body and brain and difficulty in treating late stage.

The IDSA guidelines limit choices, and are blatant in their denial of treatment options which makes life even more difficult when people can't get treatment locally. They force families to travel out of network and out of state to find help for a complex infectious disease, which untreated, can become chronic, disabling or lead to death.

The IDSA guidelines are obviously not addressing this exploding epidemic successfully. Rather, they are being used as weapons by the CT DPH medical licensing board to curtail treatment, threaten doctors who step out of line and cut costs for insurance companies at the expense of a patient's health. The combination of limited options and the over zealous enforcement of restrictive rules has managed to instill fear in our local doctors to the point that many doctors ignore their oath to "first do no harm". They have been forced to do this in lieu of keeping their licenses and their practices intact. This practice is severely limiting treatment options for CT families and causing great suffering for ourselves and our children.

Residents of Connecticut are and have been at the epicenter of a significant public health threat for decades. Lyme and other tick-borne diseases are spreading rapidly throughout the state and the nation. The growing number of sick patients, volunteer advocates, support groups and task forces are testimonial to the pain and suffering being experienced, not to mention the financial burden that Lyme and tick-borne co-infections are inflicting upon our state.

In the case of my family, longer term antibiotic treatment for Lyme and treatment of co-infections restored the quality of our health and life. Please, this bill is to ensure our rights as patients to maintain our autonomy when choosing treatments for our health care. It is allowing physicians to treat based on their discretion using clinical judgment to decide with their patients and clients which treatment modality may be best suited to restore the individual's health

Until there are tests that can detect all cases of Lyme disease in the various stages and a standard treatment which will provide a definite cure, please don't shut the door to our only viable options and our hope for some semblance of a life. Please pass HB 6200. This will allow doctors to treat their patients on a case by case basis and not by a restrictive and biased set of guidelines.

Sincerely,
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Newtown/Brookfield Lyme Disease Task Force